

Foundation for Health Care Quality
Storing and Sharing Data Workgroup

Final Comments for Discussion

June 13th, 2023

Outreach Process:

- Washington Association for Community Health Centers
- Gravity Project/SIREN
- Washington State Medical Association
- Washington State Hospital Association
- Washington Health Alliance

Specific Comments:

Comment	Draft Response
"Sex assigned at birth data" may not be necessary for employers, but other organizations may need this data.	Amend "Other organizations should not collect SAB" to "other organization should consider their need and the ethics before deciding to collect SAB".
Disability data may be useful for other organizations outside of healthcare as well.	Amend "healthcare organizations should collect disability data. other organization should consider their needs and consider collecting disability data."
Common Capabilities Question: Who should have the Master Patient Index? Is this an individual organization recommendation or a government recommendation?	
In the recommendation "consider processes for data collection, integrity, reporting, analysis, transparency, and autonomy," we may need to be more clear about what the terms mean.	Add clarity to autonomy – "offer patients an appropriate level of control over how data about them is used."

Broad Comments:

Currently we have a low response rate to our outreach. Comments received are mostly high-level, focusing on clarity and structure of the document. Some comments we have received include:

- 1) The document is long on WHAT but very short on HOW. It is trying to be a lot of things all in one place; seems to need fewer bullet items and more action-oriented information. Perhaps chunk it out into very clear subsections directed at particular audiences and provide real-world examples and tools, rather than listing multiple links.
- 2) Use more graphics/roadmaps and fewer bullets
- 3) We aren't clear on who the funders of all of this activity should be. In our assessment, funding would again attach to the audience. For example, for a provider office, who would fund the

addition of MAs and others who would be involved in the data collection? CHWs are not allowed to bill, for example, and employing one would be an additional cost to the practice. Make the business case.